

The Invisible Havoc of Prenatal Alcohol Damage

At a show-cause hearing in Texas not too long ago, the parents of a tiny baby removed from their custody brought in a photo album to document their parenting skills and dedication to the child. The judge took the album, started flipping through the pages, and called the bailiff over. There, on the first page, was a picture of the baby, sitting in a carrier on the kitchen table—nestled amid an assortment of glass pipes, powdery little baggies, and other items not normally associated with exemplary child rearing. As he leafed through the pages of adorable smelly smiles on family outings, another shot caught the judge's eye: Dad apparently swinging the 6-week-old baby by the foot. Asked to explain this behavior, Dad said, "I was holding the baby and reached into the fridge for a beer. I started to drop the beer, so I dropped the baby instead."

This baby has since been adopted by a loving family whose first task was to have his several bone fractures (suffered on different occasions) repaired. His birth parents continue to complain bitterly about "Big Brother's" interference in their family life. They give no indication of ever understanding why the baby was removed from their care.

This story may seem absurd to many of us; tragically, it is true and not totally unfamiliar to those who work in child welfare agencies. In this case, the parents show signs of cognitive malfunctioning that exceeds any current effects of drug use. They may in fact be victims of fetal alcohol spectrum disorders (FASD).¹ Their baby is at high risk to carry on the family tradition of fetal alcohol-related brain damage, as there is good reason to suspect that he was exposed to alcohol in utero.

A foster-care public health nurse in Santa Clara County, California, says that, according to her department's estimate, at least 85 percent of the children removed from their birth parents are affected by substance abuse. Her experience in the field, as well as her personal experience as a foster parent of more than 100 children, tells her that this estimate may be low. According to a study of 1992 birth data,² approximately 10 percent of live births in most California counties were "tox positive": the babies had alcohol and/or illegal drugs in their blood at the time of birth.

Nineteen-year-old Amber is serving a 90-day sentence in the women's detention facility. Her 3-year-old daughter, Jessica, is in the children's shelter. Amber is hoping the staff knows about Jessica's seizures. She has mixed feelings about this situation: she hates being locked up, but she hopes the shelter can make Jessica stop



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Only recognized by professionals in the last 30 years, fetal alcohol spectrum disorders (FASDs) are difficult to diagnose, persist in families for generations, and, without identification and treatment, almost inevitably result in broken lives. This article begins with a description of FASD: the history, nature, prevalence, causes, and effects of prenatal exposure to alcohol. Some of the unique features of FASD and the complications involved in diagnosing it are discussed. The article next explores the multigenerational roles of FASD in family dysfunction: the mechanisms by which it tears families apart, interferes with good parenting, and contributes to attachment disorders. Finally, the article discusses how the child welfare system has encountered and responded to FASD and proposes some innovative interventions and approaches.

screaming at the slightest thing (like getting her face washed) and can get her to eat (Jessica is very small). And maybe being locked up can help Amber get off drugs. She doesn't want to be like her own mother was—always high or drunk.

Amber and Jessica are two links in the familial chain of neurological dysfunction caused by exposure to alcohol in utero. Jessica's tactile sensitivity, small size, and inability to self-soothe are telltale signs of some kind of organic dysfunction; Amber has an IQ of 80, a diagnosis of attention deficit/hyperactivity disorder (AD/HD), and very small teeth.

The grandmother of a recent patient at the FASD Diagnostic Clinic³ reported five generations of addiction—and five generations of academic failure, early pregnancy, trouble with the law, and unemployment. Although five generations are more than we usually see at our Santa Clara County clinic, most of the children coming through have mothers who themselves were affected by their own mothers' drinking. (Almost all of the 80 children seen so far have come through the foster-care system.) Later in this article we dissect this generational chain of alcohol-related damage to the central nervous system (CNS) to see exactly how it is formed.

Alcohol is the only commonly abused substance known to cause birth defects, including the array of cognitive, physical, regulatory, and emotional dysfunctions referred to as FASD. Stimulants, opiates, and hallucinogens have not been shown to directly cause birth defects, although harm is done indirectly to the growing fetus in the presence of these substances. The effects of drinking on the fetus during pregnancy are not well understood by the average person, and indeed professional communities largely remain ignorant of the problem. People intimately involved in the care of FASD children, on the other hand, are experts on the severe symptoms, peculiar habits and tastes, exhausting behaviors, "moral retardation," and difficulty with learning that are part and parcel of fetal alcohol spectrum disorders. They just don't know what to call it, because, as one foster

grandmother put it, "every doctor in the book called it something else and told me to take another damn parenting class!"

HISTORY

Damage to children from prenatal alcohol has been noted since earliest times. In ancient Carthage, the bridal couple was forbidden to drink wine so they would not conceive a defective child. Aristotle observed that "foolish, drunken, and harebrained women most often bring forth children like unto themselves, morose and languid."⁴ And the Bible, in Judges 13:7, commands: "Behold, thou shalt conceive and bear a son: and now drink no wine or strong drinks."

The current understanding of FASD began to unfold in 1968, when Dr. Paul Lemoine and co-workers in Nantes, France, described 127 children born to alcoholic mothers. The pattern these children shared included consistent physical anomalies, small size, and ceaseless agitation.⁵ At the same time, during a study of failure-to-thrive infants in Seattle, only one common factor could be found: each of the babies had an alcoholic mother.⁶ In 1973 this birth defect gained worldwide attention through an article in *Lancet* that carefully described the constellation of physical features that accompanies FASD (a consistent pattern of widely spaced eyes, small palpebral fissure, flat philtrum, small chin, thin upper lip, and small overall head). By 1978, 245 people with fetal alcohol syndrome (FAS) had been identified, the "FAS face" was widely considered to be uniquely alcohol related, and prenatal alcohol exposure was described as the most frequent known cause of mental retardation.⁷ Since then, a vast and mushrooming body of scientific evidence has shown beyond a doubt that prenatal alcohol exposure does indeed damage the fetus.⁸ Today, brain imaging techniques are being used to pinpoint the most affected areas of the brain, and sophisticated arrays of neuropsychological testing illuminate the resulting deficits in functioning.

In the last decade, the use of advanced technology has made clear that this “face” of FAS is more an artifact of timing (exposure during the third week of pregnancy) than the sole defining marker of fetal alcohol damage. According to a recent estimate by eight of the principal FASD researchers, victims of FASD who do not display the telltale features outnumber those who do by at least three to four times (these symptoms, without the facial features, are most popularly known as “fetal alcohol effects” [FAE]).⁹ Indeed, these researchers believe that their estimate—that one out of a hundred people have alcohol-related brain damage—is conservative.¹⁰

Despite this plethora of conclusive research, the idea that drinking could harm the fetus has met with considerable controversy, and, despite current and incontrovertible evidence, the controversy persists to this day. Anchoring the extreme end of such denial, the Yale Center for Alcohol published a brochure in 1955 asserting that the “old notions about children of drunken parents being born defective can be cast aside, together with the idea that alcohol can directly irritate and injure the sex glands.”¹¹ This position was not entirely unreasonable at the time, given that it predated the modern “discovery” of FASD by two decades.

The present-day argument against the dangers of consuming alcohol during pregnancy is largely a passive one: fetal alcohol damage is widely ignored. FASD is rarely covered in medical school—in fact, a recent study found that only 17 percent of today’s ob-gyn texts recommend abstinence during pregnancy.¹² Physicians argue, “We don’t know if this child’s problems really stem from alcohol”; “We don’t want to label children”; “If we diagnose it, we have to treat it, and we don’t have the resources to do that”; “I wouldn’t want to shame the mother.” Ob-gyns have been heard to tell mothers to have a daily beer to relax.¹³ Physicians are not the only professionals who should know about FASD but don’t: there is practically no training on the subject in social work, mental health, juvenile justice, and other systems responsible for the care of people at risk.

Understandably, given the paucity of information about FASD, much of the public and private reaction to the behavior of fetal alcohol-affected people is strikingly parallel to the view of addiction prevalent two generations ago: these behavior problems are the result of willful opposition to authority or good sense, and if the person wanted to make a better life he or she would just buckle down and do it. Organic causes are rarely hypothesized by parents, teachers, probation officers, judges, or the public at large—bad behavior is a moral issue, the product of deliberate, premeditated, willful choice.

CAUSES

In spite of hard evidence of its widespread harmful effects, drinking during pregnancy persists. In part this persistence is due to physicians’ advice to pregnant women that a drink or two doesn’t hurt; in part it is caused by conditions of living that beg to be softened by a little daily oblivion, in part by cognitive impairment (including not being aware that one is pregnant), and in part by addiction. Uncounted numbers of children have been harmed by their mothers’ attempts to self-abort by consuming huge amounts of alcohol and other substances.

How much drinking can cause damage? Research evidence on the cellular level and from some animal studies is unequivocal: exposure to as little as one dose of alcohol has been demonstrated to hamper the ability of migrating brain cells to stick to their destined spot on the cortex.¹⁴ Research conducted on children with low levels of prenatal exposure to alcohol has been contradictory, however. There is actually little solid evidence that one drink or even two a day causes measurable harm in humans,¹⁵ although one study with rhesus monkeys demonstrates a connection between moderate drinking and irritability, hyperactivity, and rigid problem solving.¹⁶ Studies of pregnant mothers who had an average of 14 drinks a week or were engaged in similar “moderate drinking” do show a decrease in memory and learning; these studies did not, however, note whether the weekly quantity was consumed in a couple of sit-

tings. Most research suggests that a high blood alcohol level is the most important factor in fetal alcohol damage and that binge drinkers are the most frequent mothers of FASD children (a binge consists of four or five drinks in a sitting, depending on the expert cited). In any case, one of the large 40-ounce malt liquors so favored by people without a lot of money to spend on intoxication contains the alcohol of more than four standard drinks—so drinking one “40-ounce” can therefore qualify as a binge and can significantly harm the fetus.

And what exactly happens to the fetal brain to cause this damage? This is still being explored, but there are at least three mechanisms currently documented: abnormal migration patterns of cells on their way out to the cortex, reduced cell adhesion (as noted above) once they reach their destinations, and abnormal cell death all along the way. The cells actually behave a little like drunks, wandering around, sliding off their bar stools, and then passing out.¹⁷ Nothing to take lightly, of course—the result is awful, but the comparison is hard to resist.

Does heavy alcohol exposure always cause brain damage? No one knows yet. There is no evidence

that even high doses are universally destructive to the growing brain. Several factors in combination with alcohol appear to make such damage more likely, such as other drugs, tobacco, poor nutrition, stress, and poverty.

EFFECTS

The primary disabilities of FASD have been described by researchers, clinicians, and caregivers. While a common caveat in FAS/E thinking is that there is no one profile and that every person is different, the core disabilities listed in the table occur with great frequency.

INTERACTIONS WITH PSYCHOLOGICAL, ENVIRONMENTAL, AND BIOLOGICAL FACTORS

It is rare that FASD exists in a pure state outside the domain of lab rats. Even in rural South Africa, where vineyard workers are paid in the fruit of their labors (wine, called “dop”) and few people use drugs, the alcohol exposure is still layered with other influences

Core Disabilities of Fetal Alcohol Syndrome Disorders

Cognitive

Lowered IQ
Widely varying abilities
Math disability
Poor memory
Fluctuating capacity from day to day
Poor spatial orientation
Little self-awareness, reflection
Inflexibility of thinking

Executive Functioning

Impaired planning
Bad judgment
No ability to delay gratification
Little impulse control
Future orientation missing
Disorganization
Poor focus, concentration

Emotional

Intensity, urgency
Little ability to recognize feelings
Little ability to articulate feelings
Mood disorders
Rage disorders

Interpersonal

Inability to read social cues
No empathy
Poor bonding
Inability to distinguish truth from fiction
Externalization of blame
Excessive demand for attention

Medical/Neuromotor

Sensory integration disorders
Poor balance, coordination
Eating, sleeping problems
Allergies, asthma, ear infections
Heart and kidney problems
Hyperactivity
Seizures

Speech/Language

Superficial fluency
Talkativeness
Parroting of others' speech patterns
Expressive language better than receptive
General delay in communication
Vulnerability to mental illness

on behavior and learning. The study that accounts for parental factors (such as IQ or disorders of thinking, sensory integration, and emotional regulation) has not yet been done. Nonetheless there is sufficient knowledge to make some generalizations about what happens to a person when there is inherited vulnerability to mental illness or substance abuse, impoverished environment, poor parenting, trauma, or loss—resting on the very shaky foundation of a nervous system damaged by prenatal exposure to alcohol.

First, the more the CNS is weakened, the more likely it is that inherited vulnerabilities to mental illness and addiction will be exacerbated. The most commonly held theory of mental illness is that in the vast majority of cases, a predisposition to a particular imbalance will remain latent unless the person is exposed to extraordinary stress. FASD causes chronic, severe stress as a result of the person's feeling—and reality—that he or she is different from others and is unable to “do life,” combined with the financial, legal, interpersonal, or health disasters that so often ensue. Mental illness and addiction are among the most frequent concomitants of prenatal alcohol damage.

Second, FASD is both worsened by and further perpetuates the financial, legal, interpersonal, and health disasters that often accompany poverty. Children of middle-class parents with plentiful resources for support are more likely to have their needs met. Children with FASD have a great many more needs, difficult for even the most energetic, skillful, and devoted parents to meet; the consequences of not meeting those needs are dramatic and destructive. Parents with less than optimal resources are likely to be caught in snowballing chaos and tension as their FASD children explode, don't obey, don't learn, don't talk, and begin to act “bad.” Without therapists, respite care (trained child-care providers available to take over for hours or days at a time), support groups, medical insurance, or good schools, the parent of a child with FASD must contend alone with an incomprehensible and intense source of unpleasantness. These children are eminently “abusable”: parents whose own ropes are frayed by the stresses of poverty may be driven to extreme measures in their

attempts to control children who constantly disobey, who rarely express love or pleasure, and who scream with frequent and intense upset. Juvenile hall is filled with children like these.

When we add in a prenatally exposed parent to this mix of environmental (poverty) and genetic (inherited vulnerability to mental illness) difficulty, we have a combination of elements that snowball into inescapable disaster without considerable outside help. Take just one element of poverty, unpleasant sensory stimuli (cold, bad smells, noise, dirt). Most of us can cope with such stimuli without unduly throwing tantrums. People with the sensory integration difficulties of FASD, on the other hand, are easily thrown by such sensory triggers into extremes of mood or behavior, occasioning further decrements in their living situation. Poverty brings more than unpleasant stimuli, of course, and the chronic stress, unpredictability, social stigma, and isolation that are found on the margins of society each contribute another profoundly disorganizing layer to the life and functioning of a parent. If, on top of all that, a parent is trying to raise a very difficult child, everybody winds up suffering—parent, child, and society. The child with FASD in such a family will not only receive very few of the supports needed in order to avoid the secondary disabilities of school failure, trouble with the law, chemical dependency, and so on, but the disordered and fragile nervous system of this child also will be further disturbed by the chaotic parenting of the FASD parent.

Third, the psychogenic factors that assault so many of the children who require public services—loss, trauma, violence, abuse, neglect—can cause neurological changes in their own right. Stress hormones can go on permanent “red alert”; the neural fabric involved in giving and receiving love can become impenetrable; central fear-related brain structures can actually get bigger than normal. When these factors pour into a nervous system already jumpy, unable to figure things out, and unable to find comfort even in the best of situations, children can take on a feral quality, stealing and hoarding food, interpreting neutral stimuli as hos-

tile, remaining always on guard and ready to attack or get revenge at a moment's notice. Some girls under these circumstances may go the other way, especially if their abuse has been sexual, turning to seductiveness as a primary defense.

FLYING UNDER THE RADAR— HOW FASD STAYS INVISIBLE

If it is true that at least one out of a hundred of us has some measurable degree of brain damage from our prenatal exposure to alcohol,¹⁸ then who are we? How is it possible that all this neurological dysfunction can go unnoticed? Three reasons are postulated: the first (partial diagnoses) is vast and complex, the last (professional awareness) is simple and profoundly important, and the second (a peculiar communication quirk) may be merely interesting.

PARTIAL DIAGNOSES THAT MASK THE BROADER DYSFUNCTION

Several diagnoses jostle to explain what is actually one tapestry, albeit a wide and varied one, of dysfunction resulting from prenatal alcohol exposure. Attention deficit/hyperactivity disorder is the most common diagnosis given to children with FASD, with oppositional defiant disorder close behind. Bipolar disorder is also frequently diagnosed, as is sensory integration disorder. Attachment disorder is often diagnosed in children with FASD, even those who were adopted at birth. Exhausted and confused parents take their FASD children to clinician after clinician, looking for an explanation that fits their children, seeking treatment that might finally do the trick. An individual child who has been seen by a variety of clinicians can wind up diagnosed with attention deficit/hyperactivity disorder, oppositional defiant disorder, bipolar disorder, sensory integration disorder, and learning disability—and while none of these diagnoses is incorrect, they are all just separate parts of the same puzzle. If these disorders are treated in “silo” fashion, with a separate approach to each one, the child continues to suffer from misunderstanding and misdirected treatment. Treated with

the understanding that all these pieces are linked to prenatal alcohol exposure—which colors all of them—the child benefits from a unified and sensitive team approach.

Knowing—or even hypothesizing—the underlying cause of behavior problems to be prenatal alcohol damage gives the family, the clinician, and often the child a sense of relief, as this provides a context for the multitude of peculiar, even unfathomable, behaviors as well as the more categorical ones—the AD/HD and so on. Knowing that the child's problematic behavior stems from a whole network of brain damage and not from deliberate disobedience (or just related to unitary sets of symptoms as described above) releases the family from its relentless and futile attempts to get the child to “just stop it.” Given resources that are well versed in brain damage, especially prenatal alcohol-related damage, the family can redirect its efforts toward teaching coping skills, changing the environment, and supporting the areas of strength.

It is impossible to determine how often prenatal alcohol exposure actually is the diagnosis underlying these more formally recognized ones. Until we begin to ask about such exposure in the people being counted and studied for research we cannot give hard numbers, or even very good estimates. But as evidence from research mounts, it is increasingly logical to assume that prenatal alcohol exposure is indeed the cause in a great many cases of symptoms that manifest and are diagnosed as the conditions mentioned above and described in detail below.

Attention Deficit/Hyperactivity Disorder

The constellation of FASD behaviors that most commonly comes to the attention of educational, legal, or medical caregivers is the same as the cluster of symptoms characteristic of attention deficit/hyperactivity disorder (AD/HD). These symptoms form the core disabilities of FASD. From the list given in the table we can pick out the chief features of AD/HD: inattention, hyperactivity, and impulsivity; those familiar with this disorder will recognize the many subcategories of AD/HD here as

well as some of its more subtle accompanying features. In addition, the broader definitions of AD/HD include co-morbid disorders that cover most of the features listed in the table: learning disabilities, sensory problems, language delay, general immaturity—even allergies.¹⁹

(It should be noted that while most researchers consider AD/HD to be largely of genetic origin, none of the well-known AD/HD studies includes information about prenatal exposure to alcohol. The genetic theory holds that because AD/HD is more often found in immediate family members than otherwise, it must be inherited. Further “proving” the genetic link is that identical twins are more likely to share AD/HD than fraternal twins. What is not considered is that alcoholism is a family tradition, passed down through the generations. Drinking runs in families at least as much as AD/HD runs in families; AD/HD runs in drinking families; drinking runs in AD/HD families. There is more confluence of FASD in identical twins than fraternal—and the central constellation of FASD characteristics is made up of the symptoms of AD/HD.

Oppositional Defiant Disorder and Conduct Disorder

By far the most common diagnostic category in the juvenile justice system is oppositional defiant disorder (ODD); a scattering of diagnoses of ODD's more dangerous relative, conduct disorder (CD), also exists. A discussion of the general utility of these two diagnoses will have to wait for another time, but their relation to FASD must be explored for a moment: that is, FASD may lead to behavior that manifests as ODD in youth. When a person can't communicate his or her needs very well, can't figure out the cues or feelings of others, doesn't get the “big picture,” is often physically uncomfortable, does badly in school and at home, can't organize or even remember tasks or materials—and has everybody yelling at him or her to just try harder—we have a recipe for resistance and defiance. As one of our juvenile hall youth put it, “It's better to be bad than stupid.” All 10 of the juvenile offenders seen in the

FASD clinic so far have received diagnoses somewhere along the spectrum of FASD, and all arrived with previous diagnoses of CD or ODD. Many more of our offenders with these diagnoses are screening positive for FASD;²⁰ they just haven't been formally diagnosed.

Attachment Disorder

Attachment disorder is perhaps the most problematic diagnosis in the fields related to child welfare, as it so often portends placement failure and misery for all involved. Difficulties with bonding are usually attributed to negative experiences with the first caregiver. Both neglect and abuse can cause the unprotected heart of the infant to close, walling off vulnerability and tenderness from anyone who threatens to come near. Attachment difficulties are common among children of substance abusers. Attachment disorders at their most extreme manifest as truly sociopathic behavior: lying, stealing, cruelty to animals, fire setting, deliberately causing a great deal of trouble to others. In general, children with extreme attachment disorders are unmoved by human kindness or approval and seem to get pleasure from hurting others, especially people who love them.²¹ The puzzling appearance of attachment disorders in children who were adopted at birth by caring, responsible parents has prompted questions about the neural networks responsible for reciprocal affection and empathy. While these questions remain largely unanswered, many observers of early-adopted FASD children with attachment problems hypothesize that the combination of organic conditions (very poor memory, lack of cause-and-effect thinking, sensory over- or underreactivity, language delay) and psychological ones (frustration and chronic failure) synergistically produce many of the symptoms of attachment disorder traditionally thought to result from bad parenting. Again, proper diagnosis is needed. For example, one of the most successful treatments for attachment disorder is “holding therapy,” which, to a child with the tactile defensiveness often found in children with FASD, would be traumatic rather than therapeutic. If there

has been prenatal alcohol exposure, this cluster of symptoms may manifest as attachment disorder, but the roots of this disorder will be exacerbated by, if not solely a result of, organic brain damage. Without recognition of such organicity, treatment may be less successful or even backfire, as the lack of bonding would be understood to be of purely psychological origins and treated as such, ignoring any alcohol-related aspects as mentioned above—frustrating for all participants in any such therapy.

Sensory Integration Disorder

Sensory integration disorder (SID) is one of the core clusters of disability associated with prenatal alcohol damage (but, like the other disorders outlined in this article, it is the FASD field that recognizes this relationship, not the SID field). Larry Silver describes children with SID in the foreword to *The Out-of-Sync Child* by Carol Kranowitz:

These children ... have problems developing the ability to process information received through their senses ... interpreting sights, sounds, and sensations of touch and movement. They ... become unusually upset by bright lights or loud noises, or by being touched or moved unexpectedly. They also ... have problems controlling, orchestrating, and using their muscles effectively. When it is hard for them to coordinate groups of large muscles ... and/or small muscles ..., they ... have trouble mastering running, jumping, hopping, or climbing. This difficulty getting their hands and bodies to do what their head is thinking creates problems with ... many other essential life skills.²²

Kranowitz further explains:

Inefficient sensory intake: When our brains take in too little or too much sensory information, we can't react in a meaningful way. Taking in too much information is called hypersensitivity ... [To compensate,] we avoid sensory stimuli that excessively arouse us. Taking in too little information is called hyposensitivity ... [To compensate,] we seek extra stimuli to arouse ourselves. ... Neurological disorganization: A. The brain may not receive sensory data because of a "disconnect," or B. It may receive

sensory messages inconsistently, or C. It may receive sensory messages consistently but not connect them properly with other sensory messages to produce a meaningful response. ... Inefficient motor, language, or emotional output: The brain is inefficient at processing the sensory messages, thus depriving us of the feedback we must have in order to behave in a purposeful way.²³

A person with some version of SID will be out of sync with the rest of the world and unable to modulate responses no matter how much he or she might wish to. Some descriptions of children with SID go beyond problems of sensory integration, however, into areas more properly captioned "executive functioning," especially where planning and judgment are impaired (as described in the last paragraph). This extension raises the question of more extensive neurological dysfunction—another example of one perfectly good subcategory of symptoms being mistaken for the more comprehensive set of symptoms associated with FASD.

Borderline Personality Disorder

The diagnostic category most likely to capture the core FASD personality traits is borderline personality disorder. With its intense dysregulation of mood; identity disorder; frequent compulsive disorders like substance abuse, sexual abuse, or gambling; and the difficulty its subjects have in maintaining stable employment or relationships—along with a tendency to manipulate and lie—borderline personality disorder (BPD) is a near-perfect match with FASD. Private conversations with clinicians suggest a pattern of alcohol abuse among mothers of BPD patients. Psychotherapy is known to be difficult with borderlines, perhaps because the "issues" may really stem from brain damage rather than inner conflict or unconscious motivations.

Bipolar Disorder

Another common diagnosis that purports to explain behaviors of people with unrecognized FASD is bipolar disorder. As with AD/HD, bipolar symptoms are certainly part of the package of fetal alcohol damage,

especially in adolescence, when the mood tends to swing from depression to rage to irritability, unfortunately bypassing the euphoria that adults with bipolar often enjoy. Since this mood disorder is seen to affect cognitive, emotional, interpersonal, and executive functioning in normal people, it is natural to give it “primary disability” status in people with a whole raft of otherwise undiagnosed brain damage.

Summary

Any of these diagnostic categories is partly accurate; the problem with each is that it does not begin to cover the whole network of dysfunction suffered by people with alcohol-related brain damage. Worse, many clinicians, using these categories, attribute to their patients purposeful control over many of the maladaptive behaviors that make up the diagnosis. Most often, people with FASD end up labeled as “bad”—even if they carry other diagnoses that purport to explain the behaviors—unless their range of symptoms is grouped together as a whole and identified as FASD.

TALKING THE TALK

In addition to the partial diagnoses that siphon off understanding of the whole, FASD is difficult to recognize for at least two other reasons. A major contributor to the “stealth” quality of this condition is a language feature known as “superficial fluency”—the ability to sound as if one is carrying on a meaningful conversation when in fact very little information is being exchanged. Often the FASD individual has difficulty articulating his or her own real feelings and thoughts, and difficulty grasping the meaning behind others’ utterances, but can, with relative ease, produce a reasonable facsimile thereof! So often in the child welfare field we hear a parent swear to “do whatever it takes to get my baby back”—without a clue what that may be, little ability to find out, and even less ability to match actions to the words. If we don’t listen carefully and double-check what we hear, we may think the person’s cognitive processes are in fine working order ... and that his or her noncompliance is therefore willful.

LACK OF PROFESSIONAL AWARENESS

The third reason FAS/E is not recognized is that few clinicians are trained to look for it. The aforementioned diagnoses (except sensory integration disorder) are in the DSM-IV-TR and ICD-9; FASD is not.²⁴ The closest we find is “personality change due to a medical disorder.” Clinical practice lags far behind the rapidly growing body of research on FASD, as can be seen in an ob-gyn’s comment last year: “FAS? I didn’t think there was much of that around any more.” A neonatologist asked, “Don’t they outgrow it around two or three?” The charge nurse at the clinic in the women’s jail in Santa Clara County insisted on transferring a caller (inquiring about an FASD referral for an inmate) to the ob-gyn, since she thought it had to do with fetal health. And the receptionist at a county clinic thought she heard “fatal alcohol syndrome” and wanted to connect the caller to the infant mortality office.

In addition to—or perhaps as an outgrowth of—the fact that there is almost no teaching about FASD in medical schools, extremely few sources of complete diagnosis exist in the United States. The University of Washington originated a systematic diagnostic approach that has spawned other diagnostic clinics around the state and a few in the northern Midwest.²⁵ Our clinic in San Jose, California, is modeled after this approach as well and is the only source of fetal alcohol spectrum diagnosis south of Portland. (See “Diagnosis,” later in this article, for further discussion of the diagnostic process.) There may be others, but people around the country describe great difficulty in finding anyone who understands, let alone who can diagnose, this fabric of disorders.

PREDISPOSITION TO NONPRODUCTIVE OR EVEN CRIMINAL BEHAVIOR

The connection between AD/HD and delinquency is well documented and intuitively sensible: poor impulse control, hyperactivity, and distractibility are not found in the personality makeup of solid citi-

zens. As noted above, a good many of the FASD behaviors fall into the AD/HD realm, with a few added features that make bad behavior that much more likely. These include (sometimes) a lower IQ, (usually) a significantly lower level of adaptive behavior, severely impaired executive functioning, inflexibility of thinking/rigid problem solving, explosive or rage disorders, brain-based difficulty in telling truth from fantasy, and sensory integration difficulties.

Amber used to take Ritalin. It seemed to help her in school, but her mom ran out of medicine and never got around to getting more—she kept forgetting and didn't know where to go for it anyway. Amber has always had a hard time keeping track of the details of her life. Now as an adult she keeps losing her calendar and forgetting her appointments—and she sometimes gets lost when she sets off for the doctor, counselor, or probation officer the judge tells her to see. She is in jail this time because she got picked up on a bench warrant for not showing up in court. She also loses track of the past and future, living mostly in the present. So she doesn't make arrangements to take care of business until the last minute, and usually that doesn't work out well. When she can't find a ride, she gets really upset and can't think of any other way to get where she needs to go; she usually just gives up because she feels so awful. It doesn't occur to her to call anyone. Whenever the judge or probation officer asks her what happened, she tends to make up some story that she thinks will keep her out of trouble. She tends to be wrong about that, because it's generally a pretty flimsy tale.

IQ

Some people with FASD have average or above-average intelligence as measured by IQ tests. More often, prenatal alcohol damage has affected general cognitive functioning (the average IQ of people with FASD is 85.9—in the low-average range).²⁶ In addition, FASD can cause severely impaired cognitive ability and is now considered to be the primary known cause of mental retardation.²⁷ Probation staff involved in special education referral at the Santa

Clara County Juvenile Hall, for example, estimate that three-quarters of their referrals fall into the 65–75 range of IQ, hovering around the cutoff of 70 for mental retardation. They further estimate that upwards of 90 percent of those referrals were exposed to alcohol in utero. With this reduced capacity to reason, remember, solve problems, organize information, or grasp concepts, poor decisions are much more likely. One of the most common categories of these poor decisions among juveniles is related to gang activity: an adolescent with impaired ability to think things through is a good candidate for gang-related tasks that carry the highest risk of either getting caught or getting hurt; gang leaders instinctively know this and use it to great advantage. Such vulnerability carries through to adulthood, especially among males. For adult females, a common category of such ill-informed decision making is relational: hooking up with a destructive male may seem a fine idea at the time, if immediate needs for food, shelter, attention, or drugs are met. Thinking of future consequences is out of the question for people with FASD, even more so for those with a low IQ.

ADAPTIVE BEHAVIOR

Prenatal alcohol exposure impairs the ability to “do life”—to use common sense, solve problems, and act appropriately in personal, social, and community situations (known as “adaptive behavior”)—even more than it affects IQ. The average score on the Vineland Adaptive Behavior Scales (VABS) done in a study by Streissguth's group on adults²⁸ was 65.9, with 100 being average (as on IQ tests). This score indicates a severe impairment, an ability to function at a level roughly equivalent to that of a 10-year-old child, and not a particularly mature one at that. Very frequently, we see patients at the FASD clinic whose IQs are in the normal range but whose VABS scores are in the severely impaired range. These are children whose teachers and parents are completely baffled by their inability to meet expectations based on their normal “intelligence” scores. Caregivers assume deliberate defiance when these children cannot live

up to their apparent potential. Authorities supervising FASD adults are quick to assume resistance, manipulation, or sociopathy on the part of their charges when the latter do not display the normal capacities predicted by their IQ test scores.

Postnatal impoverishment of environment, trauma, abuse, or neglect can certainly influence adaptive behavior. Nevertheless, many children with FASD whose postnatal environments have been rich and loving score poorly on the VABS. Adaptive behavior is largely determined by the general category of brain activity known as “executive functioning,” discussed below.

EXECUTIVE FUNCTIONING— THE BIG PICTURE

Executive functioning is said to be that which distinguishes humans from animals and is carried out largely in the frontal lobes or the connections to those lobes. It includes the ability to plan, make good judgments, put off gratification, connect cause and effect, empathize with others, take responsibility for actions, imagine a future, remember the past, and connect the two with the present.

Amber had agreed with her caseworker that she would come to the center the following Wednesday for supervised visitation with her daughter. The caseworker urged her to get her ride set up that day, and Amber said she would. By the time she got home, she told herself she had almost a whole week to call her ride; hungry and tired, she ate dinner and fell asleep. Wednesday arrived, and Amber was jolted by the phone call from her caseworker reminding her of the appointment—she had thought that she still had lots of time.

This appointment might as well have been in the next lifetime for all Amber knew. As well-known AD/HD researcher Russell Barkley notes, where normal people can imagine a future of around six to eight weeks, people with AD/HD can imagine a future of about eight hours. This inability to organize into the future is endemic to FASD.²⁹

For people with alcohol-related brain damage (and many people with brain damage in general), the

inability to imagine a future is consistent with a general inability to see anything that is not right in front of their noses. Time, space, truth, and other people are the most problematic dimensions here—as they are for most of us, but much more dramatically so for people with FASD.³⁰

To get the idea of executive functioning (present and absent), imagine, literally, a big picture. There is a lovely sailboat in the sunshine on a calm blue ocean; birds fly above and fishes doubtless swim below. An enormous steamship heads directly for the sailboat. Asked what the picture is about, you might say something like, “A big boat is going to crash into a little boat.” Now imagine you are standing one foot away from this picture and you can describe only what is right in front of you. As you step from one spot to the next, your answer to that question will change, depending on the section of the picture you’re facing: “It’s about a sailboat. ... It’s about some birds. ... It’s about a steamship.”

People with FAS/E tend to see only what is right in front of their noses at any given time. This tendency is independent of IQ, upbringing, other talents, or even intention. “Getting the Big Picture” is the general caption for the whole array of executive functioning. If we can see only the little quadrant directly in our line of vision, it is likely that we will

- not imagine a future or remember a past
- not save money or plan for much of anything at all
- nap, eat, drink, or have sex on the job, no matter what our boss thinks we should be doing
- not act thoughtfully toward other people or understand their reactions when offended
- forget what we came into the room for
- drive through the pesky red light if we’re in a hurry
- not be able to explain our actions
- not understand that our actions have consequences

- take things that appeal to us even if they belong to others
- leave messes for others to clean up
- not be able to predict what will happen

And least likely of all is that we will make good parents.

Poor executive functioning is probably behind most of what we normally call “irresponsibility” and behind a great deal of what we attribute to deliberate bad choices and weak moral character. It is an inability to understand abstract concepts like responsibilities, good choices, and strong morals. People with FAS/E can only parrot these principles by rote; they cannot apply them meaningfully to their own lives.

INFLEXIBILITY AND EXPLOSIVENESS

To this far-reaching bundle of big-picture-challenged behaviors, we add a few features of FAS/E that can push a merely wasted life into a destructive one. The brain-based traits of inflexibility and explosiveness are particularly dangerous and often occur together, igniting an all-too-common response to frustration: “If at first you don’t succeed, throw that sucker across the room!” This behavior pattern, identifiable in early childhood, does not lead inevitably to a lifetime of violence, but it certainly makes thoughtful, productive responses less likely. Good parenting in the face of such habitual reactions, especially parenting a frustrating and difficult child, becomes impossible.

LYING

Another problematic and common side of prenatal alcohol-related brain damage is the tendency to lie. “Moral retardation” appears with FASD even where a child has been adopted in infancy and consistently taught the value of honesty. It is one of the most heartbreaking experiences of adoptive families that their children persist in behaving like street urchins in spite of the good parenting they have received. There is speculation that the thinner corpus callosum (the part of the brain responsible for connecting

the left hemisphere, or language centers, with the right hemisphere, or action centers) often seen in people with FASD may be at least partly responsible for this compulsive and often crazy lying, as the verbal part of the brain scrambles to come up with some approximation of the “right answer,” having only a rickety little bridge across to the lived experience residing in the action, or behavior, part of the brain.

SENSORY DIFFICULTIES

For most of us, the five senses are calibrated to a level of sensitivity that allows us to enjoy the incoming information they convey and alerts us to danger or need through discomfort. For some people, the level of sensitivity is either too high or too low or both in any or all of the senses. Prenatal alcohol exposure often causes such imbalance: the tags on shirt collars are irritating, only certain foods taste right, one has to keep changing body position, the bell at school sets off a flight reaction—or, in the opposite direction, wounds are not noticed, food is rejected even when needed, sleep is the last thing on a child’s agenda, even when he’s tired.

An adult with sensory difficulties may not be able to tolerate the bright fluorescent lights in the Alcoholics Anonymous meeting room, for example, and bolt halfway through every meeting without any idea of what is setting off this reaction. Another might be a sensation-seeker, doing risky things just to feel alive. Inmates in prison who have trouble knowing where their bodies are in space may bump into fellow inmates and spark a reaction resulting in bodily harm without any intention of starting a fight.

What turns sensory integration difficulties from private discomfort into troubling behavior has to do with the added effects of other FASD-related features: explosiveness, poor ability to delay impulses, and impaired executive functioning. Chronic discomfort makes it hard for anyone to remain cheerful and productive; people with FASD are quicker than most to get upset, slower to calm down, and the least likely to address basic needs like nutrition, shelter from the elements, or rest, let alone a toothache. To

top it all off, drugs and alcohol offer an appealing respite from all the internal and external noise.

So we have a person who is always upset and in constant discomfort without reliable remedy, suffers from poor impulse control and rage attacks—and is either high, coming down, or looking for the where-withal to get high again.

WHAT HAPPENS IN THE ABSENCE OF APPROPRIATE INTERVENTION: SECONDARY DISABILITIES

The primary disabilities of brain damage resulting from prenatal alcohol exposure were listed in the table shown earlier and outlined in detail above. These organic vulnerabilities can lead to “secondary disabilities”—troubling or dangerous behaviors—if they aren’t properly identified and treated (for information on appropriate interventions, see the section “Where Are We Now, and What Can We Do?”). In a seminal series of studies spanning over 15 years and still going strong, Ann Streissguth of the University of Washington has followed a group of 500 people with FAS/E,³¹ finding that the following secondary disabilities develop in the absence of appropriate intervention:

- *Disrupted school experience*, stemming from attention problems and repeatedly incomplete schoolwork, had plagued 60 percent of the adults and adolescents. Behavior problems in school fell into the categories of not getting along with peers (60 percent) and being repeatedly disruptive in class (55–60 percent).
- Sixty percent of the adolescents and 14 percent of the children had been in *trouble with the law*; shoplifting and theft were the most frequent types of crime.
- Fifty percent of adolescents and adults had been *confined*, either in mental health programs, inpatient drug and alcohol treatment, or jail.
- Forty-nine percent of adolescents and adults and 39 percent of children had displayed *inappropriate sexual behavior*.

- Of people who were at least 21 years old, two additional secondary disabilities were noted: *dependent living* characterized 80 percent of the sample, and 80 percent had *problems with employment*.

Streissguth’s explanation for these high levels of secondary disabilities found in people with FAS/E is that the primary disabilities of permanent organic brain damage are hidden, leading schools, families, the justice system, and society at large to expect normal behavior and reasoning from them. Without a low IQ score, obvious mental illness, or physical signs of birth defect, societal protection is lacking, and blame or punishment is all too often the only response.

This research also examined risk and protective factors associated with secondary disabilities. Risk factors were those that were most associated with elevated rates of secondary disabilities; protective factors resulted in lower rates. Protective factors included

- living in a stable and nurturing home
- not having frequent changes of household
- not being a victim of violence
- having received developmental disabilities services
- having been diagnosed before the age of 6
- having a diagnosis of FAS (with facial features) rather than FAE (normal face)
- having an IQ score below 70

The last two factors may seem counterintuitive. The reason that FAE leads to worse outcomes than FAS is that FAE is truly invisible—at least with FAS there is a chance that the facial features will be recognized as a birth defect signaling brain damage, and the resulting behavior will be interpreted accordingly. The advantage of lower IQ is similar—the odd or irresponsible behavior of a mentally retarded person will more likely be met with increased services and support, not punishment and shame.

Streissguth's primary conclusion from this study was a strong recommendation that early diagnosis be made available wherever warranted, so that support services could be mobilized, appropriate educational and parenting practices could be implemented, and self-image could be enhanced rather than continually eroded.

IN THE CHILD WELFARE SYSTEM

The protective factors do not exist for most of the clients we serve in child welfare. By definition, few of the children coming through the dependency system have had a stable and nurturing home. Frequent changes of household characterize many, especially those whose troublesome neurology makes for disrupted placements. A high percentage of the children in our clinic have witnessed or been victims of violence. The only children receiving developmental disabilities services are the mentally retarded. Until a year and a half ago, only a few kids had been diagnosed with FASD in our county—and they were the ones with the FAS face; in most counties, such diagnosis is not available. Finally, the vast majority of people with FASD do not have facial abnormalities, and most have IQs above 70.

The girls' units at Santa Clara County's juvenile hall provide a good example of our systemic failure to respond appropriately to FASD. At any given time, at least 90 percent of the female inmates began their journey through the system with Child Protective Services. Nearly all have dismal academic histories, exhibit terrible impulse control and cause-and-effect thinking, and are substance abusers. How many of these girls actually have brain damage from prenatal alcohol exposure? It is of course impossible to know without formal screenings. But if we do the math (at least 85 percent were exposed to drugs and alcohol in utero, and one out of a hundred people in general has such brain damage), it is logical to conclude that a great many of them are so affected. If we had identified the neurological underpinning of the social, behavioral, and academic problems that appeared early on, appropriate interventions could have been made in many of these

girls' cases. Instead, most of them (by their own reports) "feel like an idiot," "just screw up all the time, I can't help it," and (probably accurately) "never will get out of this mess."

The pattern of breaking promises, failing to appear, ignoring clear orders—and then lying about it all—is not atypical of many FASD youth and adults; the ones who wind up in the juvenile justice system are those who have developed secondary disabilities because they were not identified and treated as people with the primary disabilities associated with brain damage. Youth with FASD who do not appear in the system are (mostly) those who have been supported with appropriate interventions. These lucky ones may have similar organic tendencies to fall through on promises, forget where they're going, not grasp the significance of instructions, and even confuse truth with fiction, but they have (by definition) sufficient impulse control to avoid criminal activity and have been successfully guided to a life that includes legal pleasures.

Once in the system, youth with FASD generally keep cycling through for curfew violations, association with the wrong people, drug and alcohol consumption, truancy, shoplifting, or minor sexual offenses (often a matter of accepting the wrong invitation). Normal teens, once they have been caught, want to regain their autonomy. They understand how to curb or hide their impulses long enough to get off probation. People with FASD do not have the ability, for so many reasons outlined in this article, to plan for their future, curb their impulses, or, ultimately, achieve the elusive state of autonomy. And to cement their fate, they haven't been graced with the ability to own up to their mistakes. Youth—who so often began their journey in the system as dependents of the court—graduate into the revolving door of the penal system, creating along the way another wave of drug- and alcohol-affected children.

WHERE ARE WE NOW, AND WHAT CAN WE DO?

A person with defects in executive functioning needs an outside executive—someone who will exercise judgment and make sure that the affected person's life stays on course. Practitioners in the FAS field frequently use the term *external brain* to refer to such a support system. Successful early intervention will help a child understand that he or she has some gaps in functioning, that it isn't his or her fault, and that it's important to ask for help. But for the unlucky 99 percent of kids whose disabilities are not identified, a self-image that grows rotten with shame and alienation often creates a crust of "I'm fine; my only problem is you; all I need is freedom ...," which is exactly what they do not need. As with many allergies, that which we crave the most is the thing that makes us the sickest. Though these youth crave freedom, they really need external structure. The problem is that until they are able to welcome voluntary structure they will continue to gravitate toward the involuntary kind—winding up incarcerated or on probation.

Ultimately, of course, the very best we can do is early diagnosis and intervention with the child and the family. All is not lost, however, if we have missed this critical early window. Useful responses for people of any age follow the same principles: accurate diagnosis; education of others in the person's life about the nature of the brain damage; medication support; accommodations in school, at work, and in the legal system; sentencing alternatives; and, to whatever degree possible, coaching and mentoring about the details of daily life.

DIAGNOSIS

As noted above, diagnosis is much harder to come by than it should be, and than it needs to be. The Fetal Alcohol Spectrum Diagnostic Clinic at the county hospital in San Jose began a little over a year ago and has seen roughly 80 children in its once-a-week sessions, including several youth from juvenile hall. The team is made up of a pediatric neurologist, a

speech/language pathologist, a physical or occupational therapist, a psychotherapist, an educational specialist, a public health nurse, and a psychologist. Records are reviewed in advance. On the day of the clinic visit, the patient is tested by the speech/language pathologist (standard testing of learning and memory along with testing using materials developed specifically for FASD evaluation) and the physical or occupational therapist, who checks neuromotor and perceptual functioning. At the same time, the patient's caregivers are interviewed to explore the patient's real-life behaviors and reactions. After the team has met privately to share findings and discuss diagnostic conclusions, it shares that information with the patient and caregivers, along with recommendations, resources, and reading material. The caregivers are then contacted a few weeks later to see if they have additional concerns or questions.

In our clinic the diagnosis is not a black-or-white decision—fetal alcohol syndrome or not—because we recognize that this is a whole spectrum of disorders occurring in varying severities, with or without physical markers and with varying degrees of certainty about the mother's use of alcohol. When the evidence indicates that the symptoms are likely due to factors other than prenatal alcohol exposure, none of the diagnoses along the fetal alcohol spectrum is given. If there are significant delays in at least three areas of functioning connected to organic impairment, facial features typical of fetal alcohol syndrome, growth retardation, and documented history of prenatal exposure, then the diagnosis is FAS. Far more common in the patients we have seen is a diagnosis of static encephalopathy or neurobehavioral disorder; these refer to, respectively, equivalent or more moderate brain damage, without the physical markings indicative of FAS.

EDUCATION

After diagnosis comes education for caregivers, teachers, probation officer, counselors, physicians, and, to the extent possible, the patient. Aside from specific recommendations for structuring life to

minimize meltdowns and maximize productive activity, the main recommendation is to try to view brain damage as an explanation for the irritating (or enraging, or hurtful, or destructive) behaviors of the past. Quite often this will start a ripple of changes that serves both the youth and the system. When Amber's probation officer heard that her charge had FASD, she said, "You mean when she tells me that she forgot the meeting she's actually telling me the truth?!" Some small changes were made so that Amber's memory didn't have to hold more than it was able to; her behavior on the unit has improved, and she is actually helping with unit activities.

MEDICATION

Previous diagnoses of AD/HD may have led practitioners to try medicating the FASD sufferer. Stimulants are successful with AD/HD symptoms, although research indicates that the short-acting Ritalin is less likely to work well with FAS-related AD/HD than other stimulants. Other aspects of FASD are medically treatable as well, especially the mood disorders. Parents report remarkable improvement in their children's ability to relate to others, calm down, focus, and stay put. Even parents who are philosophically opposed to medications have found them to be lifesavers with their severely FASD impaired children. Adults who chronically returned to jail for petty, impulsive acts have managed to stay out when they were given appropriate medical treatment.

ACCOMMODATIONS IN SCHOOL, AT WORK, AND IN INSTITUTIONS

If we keep in mind that an adult with FASD may have the emotional maturity of a 7-year-old and little or no ability to think in terms of cause and effect—and must cope with sensory issues that cause chronic physiological and nervous system distress—we can realize that expecting this person to "get a clue," "learn some responsibility," "just chill out," learn from consequences or mistakes, or the perennial favorite, "grow up," is a real exercise in futility, and an expensive, destructive one at that. The fol-

lowing suggested accommodations may help in various situations with FASD children and youth. They are not a complete prescription by any means, but enough to give the reader a place to start.

Accommodations for affected children in school range from those usually implemented to mitigate the effects of AD/HD—separation from distraction, greater flexibility around punishment, seating close to the teacher, permission to move when needed—to special, self-contained classes with few students and greater therapeutic/behavioral emphasis, always with an eye toward encouragement and teaching rather than pointless punishment or deprivation. Teaching the skills that other children absorb by osmosis—social, daily living, and community skills—is essential and must be multimodal, repeated, and compelling.

At work, depending on a person's specific profile of strengths and weakness, any of the following may help: a job coach, instructions either written out or illustrated in pictures, education of the supervisor regarding FASD, built-in stress relief such as a quiet refuge or someone to vent to, repetition of instructions, and forgiveness for mistakes and forgetfulness. Minimizing stress is of primary importance. For example, if the person with FASD is successful with stocking and shelving, it's not a good idea to promote this person to cashier. It would be a real disservice to the person with FASD to be bumped from a familiar and happy routine to a job that requires interpersonal *savoir faire* and nimble problem solving if he or she has a hard time with these skills (as most people with FASD do). Even though it may signify increased prestige and more money, such a promotion can cause a brain-damaged person to panic, become disorganized, lose normal behavioral controls, and fail at the job altogether. The managerial version of the Golden Rule does not apply in job situations.

In institutional situations such as group homes, jails, or other places where there is 24-hour contact, appropriate accommodations should be similarly calibrated to the profile of the person. For example, if a person's memory is poor and he or she forgets

some obligation daily, then instead of taking away privileges, caregivers should find a response that aids memory: have the client wear an alarm watch or get a brief reminder or some other humane prompt. If the client's expressive language is much stronger than his receptive abilities (talks better than listens), caregivers should check understanding by asking the person to repeat what he heard. There should be few opportunities to make bad decisions if these seem to be the only kind a client tends to make; structure should be a given, and any resulting sense of humiliation should be met with sympathy, an(other) explanation of the reasons for the imposition of structure, and an attempt to get on with life. Given the 80 percent dependent-living rate among adults with FASD, it is unlikely that the client will "internalize responsible decision making."

The common thread through all accommodations and interventions is the "external brain." If a supportive external structure is not in place and accepted, then the imposition of a punitive external structure is inevitable. But even though it is probably useless as a change agent, what normally passes for punishment is not always a negative experience; indeed, it is a common surprise to families whose FASD children wind up incarcerated that they are happier and calmer than they were at home.

PARENTING THE FASD CHILD

Children with prenatal alcohol exposure are difficult for anyone to raise, as well-prepared adoptive parents attest. A child who is quick to get upset, slow to obey, impossible to calm or console, generally complaining about some discomfort or other, and often sick would be hard enough to tend without the rage disorders, lying, or inability to read social cues, remember yesterday's learning, or express needs. These children rarely reflect back the calm, happy, interactive impression of a well-cared-for child even with the best parenting. This makes it very difficult to keep the bonding cycle going—if indeed it ever began. Otherwise healthy marriages have broken under the strain (each partner accuses the other of

causing the child's problems), and siblings suffer from the disproportionate concentration of resources the affected child receives. Well-meaning others offer advice, usually unsolicited and inevitably conflicting: "A little more discipline will fix him right up"; "Don't be so rigid, loosen up"; "Kids need to eat a balanced diet with no additives"; "Don't fight over food, kids usually get what they need"; "Spend more time with your kid"; "You need some time away"; "He'll get used to Gymboree—just keep going even though he screams his head off every time you go"; "Minimize meltdowns—if he doesn't like Gymboree, go somewhere else"; "Don't let him learn to manipulate you."

Adoptive parents raising children diagnosed with FAS/E report significant depression, exhaustion, and anxiety. When these desperate parents seek professional advice, clinicians almost invariably suggest another parenting class or chore charts with gold-star stickers. When the child doesn't respond to the methods that the parenting class swears by (and with which the other parents proudly report such success), a parent who hasn't considered organic causes will turn with the force of gravity to the belief that "something is rotten in Denmark here, and it's either the kid, the spouse, or me." Drinking and drug use have been known to begin or increase under the confusion, pressure, and shame of what looks to all concerned like a simple case of bad parenting.

NEEDS OF THE CHILD

Some experts believe that early and accurate diagnosis is the single most effective intervention for FASD. On top of this base of knowledge, appropriate services can then be gathered from the school district, county mental health, or medical staff, and parental efforts can be aimed in the right direction. A great many parents, both biological (in recovery) and adoptive, share stories of children who are now reasonably happy and productive, thanks to appropriate diagnosis and intervention. Nevertheless, enormous patience, resourcefulness, humor, and flexibility are required.

"It takes lots of extra time to raise a child like my daughter. It was like raising four children most of the time. ... When Rosee was five and had been with us only a month or so, we went walking along a tiny creek with both muddy sand and small pebbly gravel. Every step she took ended in the sandy mud and she would let out a scream. I would say, 'Walk on the gravel,' and she would step in the mud and let out another scream. Finally I reached down, showed her the gravel, and told her, 'Walk here and you won't sink.' No more problem. She hadn't been able to connect the words with the action and couldn't figure out [how] to switch to the gravel on her own."

Even mildly affected kids with FASD who are otherwise doing well can confound their parents with their inability to get the big picture, to see beyond the immediately visible: "We told him we didn't want him shooting BBs into his bedroom wall any more (there were holes everywhere), so after the wall was repaired, he put up a *paper* target and resumed shooting the BBs into the wall. When I found out, he said, of course, that he *wasn't* shooting them into the wall."

Medical problems are legion in these families. A mother reported in her post to the online support network that on one particular day she had to take her 10-year-old to the orthodontist for another tightening that would send her child into (loud) agony for the whole day, and then had to go the kidney doctor. Meanwhile, the cardiologist called to say he needed to speak to her.

This picture of good-humored, loving—albeit profoundly challenged—family life changes dramatically when the parents are affected by prenatal alcohol exposure themselves.

IF PARENTS ARE ALSO AFFECTED³²

Parents with FASD will have some combination of the following: many children and an inability to care for them, the appearance (and often reality) of detachment, denial of problems, or blaming others for problems. They may be verbally compliant but can't carry out recommendations because they are likely to be disorganized, especially with time and

money. They have a hard time delaying gratification and have little impulse control. They may be highly verbal, talking a "blue streak," but are easily victimized and gullible; they often have a history of sexual or physical abuse. On top of this unmistakable portrait of dysfunction, they tend to have nothing but positive things to say about their own or their children's behaviors and achievements—in the absence of actual feedback.

FASD parents need diagnosis (or an informed hypothesis) so that their behavior can be interpreted correctly and supports can be put in place. A functional skill assessment can help pinpoint either eligibility for disability services or the appropriate level of employment. A mentor or coach—someone who can offer support, guidance, and advocacy on a frequent basis—should be assigned to the parent. These services must be long-term and structured tightly so that crises can be foreseen and prevented; should a crisis arise, temporary crisis management must be available. Long-term or permanent birth control should be made easily available, and reliable, ongoing provision of food and shelter should be arranged.

The foregoing assumes sobriety on the part of the affected parent. If the parent is actively using alcohol or drugs, then the needs change. At this point, what may have been a workable household with support becomes unworkable, and addiction treatment must be activated. Such treatment needs to be nontraditional, as the usual 12 steps of recovery require some degree of self-reflection and big-picture thinking lacked by those with FASD. An addicted parent with FASD will also need to have some sort of buffer zone between him- or herself and substances, such as a sober living environment with close supervision and frequent drug testing.

The children of FASD parents—if somehow unaffected themselves—will likely take over the parental role and will be deeply anxious. They have been pouring the cereal and putting on the Band-Aids for the family since early toddlerhood. They have been exposed to sex, violence, chaos, homelessness, filth, and illness. These children may manifest symptoms of AD/HD that will resolve in time,

stemming as they do from the hypervigilance necessary to combat the anxiety of being in that household. They will make tremendous gains in improved surroundings.

When the children of FASD parents are also affected by prenatal exposure to alcohol, many of their behavioral problems are organically based and will not resolve. They will need to be worked around and treated. A full diagnosis should be done to assess strengths and weaknesses, and a plan of accommodations at home and at school should be mapped out. The AD/HD symptoms will need to be treated medically. Increased supervision and structure are necessary. In short, these children should live with a family that understands and has the capacity to deal with this particular disability. A management team will be needed to facilitate resources for medical care, speech and occupational therapy, special education, ongoing neuropsychological evaluation, functional skill building, behavior management focused on prevention of maladaptive behaviors—all working together to minimize of secondary disabilities.

SYSTEMIC ISSUES

The *Child Welfare Outcomes 1999: Annual Report* lists the following as “accepted performance objectives for child welfare practice”:

- Reduce recurrence of child abuse and/or neglect,
- Reduce the incidence of child abuse and/or neglect in foster care,
- Increase permanency for children in foster care,
- Reduce time child is in foster care prior to reunification without increasing re-entry,
- Reduce time child is in foster care prior to adoption,
- Increase placement stability, and
- Reduce placements of young children in group homes or institutions.³³

In fact, according to the Adoption and Foster Care Analysis and Reporting System (AFCARS), 18 percent of children in foster care in 1999 were in

group homes or institutions and the median age of children in foster care was 10.1; only 59 percent were reunified with their families during that year.³⁴ According to the Urban Institute, foster care cost at least \$9.4 billion in 1999.³⁵

We can make at least three judgments in conjunction with these statistics to illustrate the effects of FASD. These judgments may seem speculative, but they will resonate with people working in the trenches of the child welfare system. The first judgment is that many of the 18 percent of foster children who end up in institutions because of their unmanageable behavior or emotions have nervous systems damaged beyond the capacity of regular or even therapeutic foster families to care for them. The second judgment is that many of the 41 percent of foster children who are not reunified with their families spent their early years living with parents so dysfunctional that their needs went unrecognized. This lack of recognition in turn will have often allowed the children’s primary organic disabilities—almost never identified or appropriately treated—to develop into secondary, more troubling, behavioral manifestations. This development, and the 10-year median age of foster children, leads to the third judgment: that, as foster children age and their behavior worsens, they will transition to group foster homes, juvenile halls, or even homeless shelters. And—no inference here, just simple math—this system costs every American at least \$32.60 per year (as of July 1, 2002).³⁶

The composite picture shows many kids coming through foster care and graduating to correctional, substance abuse treatment, homeless aid, or other similar systems because they were not supported early on (if ever) with adequate identification of and intervention for neurological damage. (Of course, FASD is not the only reason, just the one most often overlooked.)

The message to us from the foremost researchers on alcohol-related brain damage—that early identification of FASD is the single most significant protective factor in preventing secondary disabilities—must be put into practice if we are to

begin to deal with this expensive, destructive, self-perpetuating avalanche of damaged souls. The adage in the FASD field that the (undiagnosed) “boys get locked up and girls get knocked up” can only be countered if the underlying pattern of neurological impairment caused by FASD is revealed, if families can be supported to adequately manage these difficult children, and if professionals in the legal, medical, educational, social, and mental health fields become aware of the disorder’s signs, difficulties, and interventions.

The Annie E. Casey Foundation has recently released a white paper with the following recommendations for successful permanency placement:

- Services and supports should be available to all adoptive families regardless of type of adoption.
- A network of services and supports ranging from prevention and early intervention services to in-home or residential treatment services should be available in communities.
- Services and supports should be available as needed by adoptive families at various times throughout a child’s development.
- States should track the entry and re-entry to foster care of children adopted through the public child welfare system and nonpublic agencies.
- Adoptive parents and adopted youth and young adults should be engaged in the design and delivery of postadoption services.³⁷

“The foundation does not live in the real world,” some readers can be heard to mutter. The inescapable fact remains that too many children become “throwaways”—not for lack of caring, resources, or good intentions, but because their brains don’t work right and we don’t know how to deal with them. Many children of profoundly dysfunctional homes who have managed to succeed have personalities that allowed them to recruit helpful adults into their lives. The children we’re talking about are not those children.

The foundation’s recommendations stress the development of an ongoing network of supports and services, designed with the participation of the families themselves. Families raising children with FASD know these supports must begin with diagnosis as the basis for appropriate intervention and accommodation.

NONMONETARY OBSTACLES TO DIAGNOSIS

A district attorney was heard to say, “We don’t want to get these kids diagnosed because nobody will want them if they know how bad off they are.” A pediatrician in one county’s foster system believes that birth mothers will not voluntarily bring their children for diagnosis, especially if alcohol abuse was not already recognized as a problem, because they are afraid their children may be removed (or reunification prevented) if signs of prenatal alcohol damage are found. ob-gyns do not ask pregnant women about drinking for various reasons: They aren’t sure what to do if a problem is uncovered, they don’t believe a little drinking can really hurt the fetus, they don’t want to embarrass the woman, or they don’t know how to ask.

Fear, shame, denial, and ignorance conspire to keep our communities from recognizing that diagnosing alcohol-related brain damage is as important as diagnosing allergies, autism, or diabetes. In the absence of such diagnosis, however, we stand by helplessly, pouring money and heartache into people who just “don’t get it,” and we blame them for not trying hard enough, which actually might be the case if they possessed the necessary neural circuitry necessary for the task in the first place. But they don’t. And just as we arrange the world to be a more sensible place for mentally retarded people, we need to begin to arrange the world to make sense for people who, while not mentally retarded in the legal and educational sense of the term, are certainly “common-sense” retarded and will not manage even minimally well without structure, guidance, and support.

SOME PROGRAMS THAT WORK

Sometimes this structure and guidance needs to come from the court, and in fact several court-related programs are in place and inadvertently operating on principles known to foster success with people with FASD as well as non-brain-damaged clients. The only missing element, common to all such programs, is longevity. People with serious impairments in executive functioning will need external structure all their lives; the likelihood of reappearance in the system is high without that structure in place. The following are a few representative programs that work with people whose executive functioning needs such a boost from the outside.

DRUG TREATMENT COURT

Drug treatment court is a good example of the “shorter leash” approach that works well with offenders in need of a higher degree of “external brain” than the normal person who just happens to get caught. Drug testing is frequent and random; school or work attendance is checked; in the case of youth, obedience to parents is a condition of probation and is monitored; and appearances before the judge occur weekly during the first phase. In Santa Clara County’s version of drug treatment court, there is a whole team of adjunct caregivers in court every time the person appears: a public health nurse, a social worker, an FASD/LD (learning disability)/ADHD consultant (in juvenile treatment court only, so far), a life skills teacher, and community workers, as well as counselors and the defense attorney. The circle is a firm, affectionate, often good-humored one with very few cracks to fall through—much to the chagrin of many at the beginning of the program. By the end of the process (at least a year later), however, the affection is often mutual and palpable. As part of the program, educational, physical health, medical, family, and mental health needs are monitored and met where possible. The emphasis is on celebrating success and growth while maintaining firm limits with (ideally) immediate consequences for infractions.

Santa Clara’s family drug court addresses both dependency and treatment issues, tightening the net of monitoring and support. This increased supervision includes regular drug testing, frequent appearances in court, and the involvement of social workers and mental health counselors. Needs related to other life problems such as domestic violence, homelessness, and medical conditions are recognized and addressed as they come up. Encouragement is frequent and heartfelt, coming from all members of the team, particularly the judge. Specific elements of family drug court vary across the country, but as Santa Clara’s is a model court, it represents the basic template.

MENTORING

The Parent-Child Assistance Program (P-CAP) in the state of Washington is an exemplary model of programs that use mentors, serving as an “external brain” for mothers who have the most difficulty staying clean and sober. P-CAP addresses the risks of neurological impairment and compromised home environment that threaten the children of substance-abusing mothers. Its goals are to help mothers build and maintain healthy independent family lives, to ensure that children are in safe and stable homes, and to prevent future births of alcohol- and drug-affected babies. P-CAP uses trained and supervised paraprofessional advocates who each work with 15 clients for three years, assisting in identifying personal goals; obtaining alcohol and drug treatment; staying in recovery; choosing a family planning method; connecting with community services; arranging transportation to appointments; solving housing, domestic violence, and child custody problems; and resolving service barriers across systems.

EARLY INTERVENTION AND PARENT EDUCATION

Epiphany Center is a program in San Francisco with short-term residential treatment for drug- and alcohol-exposed infants. The goal is to reunite infants with their birth parents, extended family, or an adoptive family within six months of placement.

The program includes early intervention to promote healthy physical development, positive neurobehavioral organization, positive attachment to significant adults, developmental assessment and follow-up services, case management, well-baby care, substance abuse treatment, parenting classes, life skills training, and in-home services.

SHARED FAMILY CARE

Shared Family Care (SFC) places an entire family with a host family trained to mentor and support the biological parents. Outcomes range from reunification and prevention of removal to the decision to terminate parental rights. SFC programs exist around the country: Minnesota has a Whole Family Placement Program; the Crime Prevention Association operates A New Life in Philadelphia; and pilot programs are being evaluated in California and Colorado.

ALTERNATIVE RESPONSE SERVICES

Alternative Response Services, funded by tobacco tax money in California and run by community-based organizations, addresses the families who have been reported to Child Protective Services but against whom charges have not been filed, although some level of family dysfunction is noted. This quasi-voluntary program assesses the family's needs and goals and finds resources to help meet them. If the family is entirely resistant to this process, the case is reported to the court, which then may tighten supervision.

MULTI-SYSTEMIC THERAPY

Multi-Systemic Therapy makes high-quality, on-call psychological services available to at-risk families at any hour of the day or night, in addition to regular counseling and addressing educational, vocational, or other needs. This collaborative program operates on the premise that advice or counseling must be practical in a real-life context, aimed at concrete needs and problems rather than theoretical "issues," and must stay oriented to the clients' own expressed priorities. It is an intensive wraparound-style

approach that requires specific training and monitoring for its providers.

Brain-damaged delinquent youth themselves are not only out of control but also are frequent victims of bullying and exploitation. At least three counties are now considering a separate unit for juvenile offenders with FASD, traumatic brain injury, or other organic disorders to protect them from the general juvenile hall population. Ideally, these separate units could also provide targeted education aimed at improving the youths' self-understanding and acceptance of their limitations as well as developing viable work options, life skills, interpersonal relations, and emotional self-regulation.

CONCLUSION

If Amber and her mother had been assessed years ago for the brain damage that so clearly generated their assorted symptoms of AD/HD, poor memory, and inability to plan or otherwise understand the implications of their actions—if someone had recognized that the family's tradition of early pregnancy, incarceration, and substance abuse was not entirely volitional—and if the system had somehow put in place a sort of "Big-Sister-with-teeth"—this cycle may have been broken before it repeated itself. As it happens, because a public health nurse on the drug court team recognized the signs of FASD, Amber and her daughter are headed for diagnosis and supports will be put in place for them. May it be just the first step in breaking this family's cycle of FASD.

NOTES

1. The term *fetal alcohol spectrum disorders* comprises fetal alcohol syndrome (FAS) and what used to be called "fetal alcohol effects" (FAE). People with FAS are quite small, have characteristic facial abnormalities, central nervous system damage, and a history of prenatal exposure to alcohol. People with FAE have the nervous system damage and the prenatal history. Other terms for FAE are *alcohol-related neurodevelopmental disorder* (ARND); *neurobehavioral disorder, alcohol exposed*; and *static encephalopathy, alcohol exposed*.

2. William A. Vega et al., *Profile of Alcohol and Drug Use During Pregnancy in California, 1992*, PERINATAL SUBSTANCE EXPOSURE STUDY, SUMMARY OF PROCEDURES AND FINDINGS (submitted to Cal. Dep't of Alcohol & Drug Programs by Univ. of Cal., Berkeley, Sch. of Pub. Health, Sept. 1993).
3. The FASD clinic, housed in the Santa Clara Valley county hospital, was supported by grants from the City of San Jose and the County of Santa Clara as well as a private foundation. It was modeled after the University of Washington's FAS clinic (the Fetal Alcohol Syndrome Diagnostic and Prevention Network), which uses a systematic, multidisciplinary, spectrum-based diagnostic schema.
4. Henry L. Rosett, *A Clinical Perspective of the Fetal Alcohol Syndrome*, 4 ALCOHOLISM: CLINICAL & EXPERIMENTAL RES. 118 (1980) (quoting ARISTOTLE, PROBLEMS).
5. Paul Lemoine et al., *Les enfants de parents alcooliques* [Children of alcoholic parents], 21 OUEST MEDICAL 476 (1968) (observed anomalies based on 127 cases).
6. Christy N. Ulleland, *The Offspring of Alcoholic Mothers*, 197 ANNALS N.Y. ACAD. SCI. 167 (1972); Christy N. Ulleland et al., *The Offspring of Alcoholic Mothers*, 4 PEDIATRIC RES. 474 (1970).
7. Ann P. Streissguth et al., *Intelligence, Behavior, and Dysmorphogenesis in the Fetal Alcohol Syndrome: A Report on 20 Patients*, 92 J. PEDIATRICS 363 (1978).
8. INST. OF MEDICINE, FETAL ALCOHOL SYNDROME: DIAGNOSIS, EPIDEMIOLOGY, PREVENTION, AND TREATMENT (Kathleen Stratton et al., eds., Nat'l Academy Press 1996).
9. Paul D. Sampson et al., *Incidence of Fetal Alcohol Syndrome and Prevalence of Alcohol-Related Neurodevelopmental Disorder*, 56 Teratology 317 (Nov. 1997).
10. *Id.*
11. Rosett, *supra* note 4.
12. Karen Q. Loop and Mary D. Nettleman, *Obstetrical Textbooks: Recommendations About Drinking During Pregnancy*, 23 AM. J. PREVENTIVE MED. 136 (2002).
13. Personal communication with Cindy Thibodeau, foster mother, Santa Clara County, Cal. (Oct. 9, 2002).
14. Damaris Christensen, *Sobering Work: Unraveling Alcohol's Effects on the Developing Brain*, SCIENCE NEWS, July 8, 2000, at 28.
15. ERNEST L. ABEL, FETAL ALCOHOL ABUSE SYNDROME (Plenum Publ'g Corp. 1998).
16. Mary L. Schneider et al., *Moderate Alcohol During Pregnancy: Learning and Behavior in Adolescent Rhesus Monkeys*, 25 ALCOHOLISM: CLINICAL & EXPERIMENTAL RES. 1383 (2001).
17. See INST. OF MEDICINE, *supra* note 8.
18. See generally Sampson et al., *supra* note 9.
19. RUSSELL BARKLEY, ATTENTION DEFICIT HYPERACTIVITY DISORDER: A HANDBOOK FOR DIAGNOSIS AND TREATMENT (Guilford Press 1990).
20. For an example of a screening tool, see Sandi Berg et al., FASNET Assessment Tool (FAS/E Support Network 1995).
21. See generally KEN MAGID & CAROLE A. MCKELVEY, HIGH RISK: CHILDREN WITHOUT A CONSCIENCE (Bantam Books 1988).
22. Larry B. Silver, *Foreword*, in CAROL STOCK KRANOWITZ, THE OUT-OF-SYNC CHILD: RECOGNIZING AND COPING WITH SENSORY INTEGRATION xii (Perigee 1998).
23. CAROL STOCK KRANOWITZ, THE OUT-OF-SYNC CHILD: RECOGNIZING AND COPING WITH SENSORY INTEGRATION 55 (Perigee 1998).
24. DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS: TEXT REVISION (DSM-IV-TR) (Am. Psychiatric Press 4th ed. 2000); INTERNATIONAL CLASSIFICATION OF DISEASES: CLINICAL MODIFICATION (ICD-9-CM) (Am. Med. Ass'n 9th rev. ed. 2001).
25. SUSAN J. ASTLEY, & STERLING K. CLARREN, DIAGNOSTIC GUIDE FOR FETAL ALCOHOL SYNDROME AND RELATED CONDITIONS: THE 4-DIGIT DIAGNOSTIC CODE (Univ. of Wash. Pub'n Servs. 2d ed. 1999).
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27. INST. OF MEDICINE, *supra* note 8.
28. THE CHALLENGE OF FETAL ALCOHOL SYNDROME: OVERCOMING SECONDARY DISABILITIES (Ann Streissguth & Jonathan Kanter, eds., Univ. of Wash. Press 1997).
29. BARKLEY, *supra* note 19.

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30. Sarah N. Mattson et al., *Executive Functioning in Children With Heavy Prenatal Alcohol Exposure*, 23 ALCOHOLISM: CLINICAL & EXPERIMENTAL RES. 1808 (1999).
31. STREISSGUTH ET AL., *supra* note 26.
32. Thanks to Donna deBolt and Mary Berube for sharing their schema for identifying the intergenerational presentation of FASD and how it interweaves with current addiction or sobriety.
33. CHILDREN'S BUREAU, U.S. DEP'T OF HEALTH & HUMAN SERVS., SAFETY PERMANENCY WELL-BEING: CHILD WELFARE OUTCOMES 1999: Annual Report, at I-1 (U.S. Dep't of Health & Human Servs. 2000).
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